

THE FAMILY INITIATIVE

DEPARTMENT OF HEALTH TO ISSUE NEW GUIDELINES FOR HEALTH CARE PURCHASERS

The Department of Health are currently undertaking a project called the Family Initiative, focusing on meeting the needs of families affected by HIV/AIDS.

The initiative came about because of a recognition that with the increasing numbers of families affected by HIV/AIDS, there was a need to look at current service provision and care available for this group from a health care perspective with the intention of producing guidelines for purchasers.

The initiative involves obtaining information from a programme of visits including units, clinics, statutory and voluntary organisations and individuals working in this field both in and outside London. The original plan was to use the information gained from these visits to develop guidance for purchasers of health-care. However it quickly became apparent that to sep-

arate health care issues from social care issues was going to be difficult, and it was decided that the guidance to be developed would primarily be centred on health care but that social care issues would also be highlighted.

The first round of visits has now been completed, and a second round is being arranged which will include several visits to centres outside London.

Draft guidelines are scheduled for circulation later this year.

If there are any issues you would like to raise, please contact: Jackie Tipple, Communicable Diseases Branch (Medical), Department of Health, Wellington House, 133 -155 Waterloo Road, London SE1 8UG.

BABIES GIVE LIE TO SUNDAY TIMES

In another in its series of sensationalist reports on HIV and AIDS, the Sunday Times (29 August 1993) gave front page prominence to a story with the headline "Babies give lie to African AIDS".

The story focused on a group of children at the Nyumbani home for abandoned and orphaned HIV positive children in Nairobi, Kenya. In the year since it opened, 45 children have been cared for at the hospital, only one of whom has died. The Sunday Times claims that this fact casts doubt both on the theory that HIV causes AIDS, and on the extent of the African AIDS epidemic.

However, even on the basis of the limited information contained in

the article, it is clear that there is nothing in this story that contradicts established opinion. The technique used is to set up a caricature of expert opinion, and then to demolish this opinion which no expert actually holds.

The story talks of the "HIV-positive children who health experts say, are condemned to die. Except that they are very much alive". Father Angelo d'Agostino, the hospital's founder, is quoted as saying that "According to most predictions, the children should have died within two or three months of coming to us". Is this true?

The article itself states that some of the children were subsequently found not to have HIV, though it

doesn't say how many. It is well known that the standard HIV antibody test cannot give an accurate diagnosis for up to the first

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+ four page supplement: report of the 2nd International Conference on HIV in Children and Mothers.

NATIONAL FORUM ON AIDS AND CHILDREN

The National Forum on AIDS and Children brings together organisations concerned with children infected or affected by HIV, from both the voluntary and statutory sectors.

The Forum aims to promote the interests and welfare of children and young people in relation to HIV/AIDS issues by:

- promoting an effective voice for children.
- providing a national resource and data-base.
- disseminating information about good practice.
- promoting research and training.
- identifying un-met needs and promoting service development.
- campaigning and lobbying, representing members' views to government, media and outside bodies.

ChildAIDS, the newsletter of the National Forum on AIDS and Children, is published quarterly. Views expressed in the newsletter do not necessarily reflect those of the Forum as a whole.

Contributions of articles, materials for review, or any relevant information, are welcomed and should be sent to the editor, Neil Orr, at the following address.

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**NATIONAL
CHILDREN'S
BUREAU**

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FORUM REPORT

Since its first meeting in April 1992, the National Forum on AIDS and Children has firmly established itself as a focus for those agencies attempting to improve the situation of children affected by HIV/AIDS. More than eighty such organisations from health services, local authorities, and the voluntary sector have participated in our meetings. These have addressed a wide ranges of issues including communicating with children, child protection, and the needs of older children and young people. ChildAIDS has been launched as the only UK-wide newsletter on children and HIV, and ongoing work is being carried out on children's rights and other areas.

The Forum is hosted by the National Children's Bureau, which provides a range of professional support (management, fundraising, etc.). The Forum is however an independent body, co-ordinated by a Steering Group of some of the organisations involved, such as Barnardo's, the National AIDS Trust, Positive Youth and Children in Scotland, as well as the Bureau.

Campaigning

The Steering Group has put forward two proposals for the future of the Forum, to be discussed at the next Forum meeting in February. The first is that the Forum should raise the profile of its campaigning and lobbying work (within the limits on political activity allowed by the Charity Commission). A draft statement of achievable campaigning aims will be circulated in the New Year.

Membership

The second major proposal is that we should move towards a formal

membership structure for the Forum. At present there is no clear way of distinguishing who is a member and who isn't. Clarifying this would enable the Forum to say with more authority on whose behalf it is speaking. It is proposed to charge a nominal fee to help cover postage, printing and other costs (the suggestion is £30 for national organisations, £15 for small voluntary and local organisations). Individuals will be able to become associate members (£15), receiving the newsletter and other publications.

Funding

Funding for the Forum has come from a number of sources, including the National AIDS Trust and a number of smaller grant-making bodies. A recent radio appeal has raised £7,000. The present level of funding is sufficient to employ one worker for the Forum, four days a week. A priority is to secure core funding to ensure that the Forum is able to continue its work on at least the current level.

CHILDREN'S RIGHTS MEETING

The next meeting of the Forum is on the theme of "the rights of children and young people affected by HIV," and will be held at 2:00 pm on Thursday February 10th in London (venue to be confirmed).

Among the topics for discussion at the February meeting will be: How useful is a model of children's rights in working with families affected by HIV? What rights do children have in particular areas (health, social services, etc.)? How can these rights be implemented in practice?

A Children's Rights Working Group of Forum members has been working on this area for some time, and a discussion document will be available shortly. Some of the work of this group was presented in a workshop and a poster at the recent International Conference in Edinburgh.

U K N E W S

□ SCHOOL POLICIES

A survey of health education policies in schools has found that few have policies covering appropriate actions if a pupil or member of staff is HIV positive. The survey found that only 9% of primary schools, and 9% of secondary schools had policies in this area.

A survey of health education policies in schools, prepared for the Health Education Authority by the National Foundation for Educational Research, 1993.

□ NEW SERVICES

• A new dental service is being developed for women and children affected by HIV in Hillingdon.

Details from: Clare Saunders (Senior Community Dentist, Special Needs and Paediatric Dentistry), Laurel Lodge Dental Clinic, Harlington Rd, Hillingdon, Middlesex UH8 3HD (tel. 0895 252681).

• Family Link have launched a new respite care scheme for families in Greenwich with a child with a disability or special need - including HIV/AIDS. The service is flexible, with trained volunteers able to spend time with a child in their own home or in the volunteer's home, for a couple of hours, a weekend, or even longer.

Details from: Family Link, St Mary's Church, Greenlaw Street, Woolwich, London SE18 5AW (tel. 081 317 7293).

□ EDINBURGH PLAYScheme

Body Positive in Edinburgh organised a playscheme in the school summer holidays for children aged 3 - 12 years old affected by HIV and AIDS. More than 30 children were cared for on one day a week, with trips being organised to a safari park, a steam railway and several other places.

Details from: Rosie Stark (Project Worker), Body Positive Lothian, 37-39 Montrose Terrace, Edinburgh EH7 5JD (tel. 031 652 0754).

□ SAS STOPPED

The Charity Commission has insisted that the Stop AIDS Spreading Trust stop claiming to raise money "for HIV orphans". The National AIDS Trust and the Terrence Higgins Trust complained to the Commission about the charity, which promised big financial rewards for its fund-raisers.

□ CHILDREN'S SERVICES REVIEW: WHAT ABOUT HIV?

The Specialist Children's Services Review Group has published its report. The review was one of a series commissioned by the London Implementation Group for the Government in the wake of the Tomlinson report looking at the future of health services in London. The report recommends that the number of London hospitals providing inpatient care for children be reduced from 18 to a maximum of ten, and also makes recommendations for specific hospitals.

During the (very) brief consultation period for the review, the National Forum on AIDS and Children urged the Review Group to consider children's HIV services, particularly in view of the fact that the four Thames Regions account for more than half of the children born to HIV positive mothers in the UK to date. Unfortunately however the Review Group focused on a narrow range of specialities (oncology, renal services, neurosciences, plastic and burns and cardiology), and HIV is barely mentioned in the report. It appears that recommendations with implications for children with HIV and many other conditions have been made without considering what their needs might be.

Specialist Children's Services Review Group, *Children: report of an independent review of specialist services in London* (HMSO, 1993).

STATISTICS UPDATE

• By July 31st 1993, there had been 534 reports of children being born to HIV positive mothers in the UK (300 in the Thames Regions, 92 in the rest of England, Wales, and N. Ireland, and 142 in Scotland). Of these, 203 are known to be infected, 165 are uninfected, and 166 are of indeterminate status.

In addition, 272 children (aged 14 or under) in the UK have become infected with HIV via infected blood or blood products. 197 of these are now aged 15 or over.

As of 30 April 1993, 76 HIV-infected children had died.

National Study of HIV in Pregnancy, September 1993; Public Health Laboratory Service, 19 July 1993.

RECENT JOURNAL ARTICLES

Meredith, H. (1993) Child-centred working, *AIDS Matters*, August, no.13 (advice for those seeking funds for children's services, stressing the need for long-term strategic planning to meet the needs of the child).

Fratter, J. (1993), Service opportunity, *Community Care*, 12-13, July 22 (developing services for families living with HIV, written by a member of Barnardos Positive Options team).

Francis, J. (1993), Identity crisis, *Community Care*, 16-17, August 26 (the needs of young carers looking after parents with HIV).

Davies, PM et al (1993), Risk of HIV infection in homosexual men, *British Medical Journal*, 681, 11 Sept (results of a Project SIGMA survey suggest that "Young men remain at risk of HIV transmission, but they are not more likely to have unsafe sex... than older men").

Mansfield, S. and Singh, S. (1993), Who should fill the gap in HIV disease?, *Lancet*, 726-728, Sept 18 (emphasises importance of primary care services - Gps, health visitors, etc. - in HIV).

THE MEMORY STORE

The Memory Store was developed by Barnardo's to provide a practical way of bringing together important information for children who are losing contact with their parents. Carol Lindsay Smith of Barnardos describes how the store has been used to date and plans for its future development.

The Memory Store was developed as a direct result of work with families living with AIDS who were being helped to make plans for the long term care of their children. It was clear that many of the children would lose both parents and, in some cases, siblings and other relatives as well. They would then be at risk of losing track of their family history, with no one left to pass on information about their early life, nor to help them to understand their parents' aspirations for them.

The Store is the size and weight of an attache case and includes drawers for small keepsakes, space for a video of family events and recordings of the parent's voice, and a Memory Book of loose leaf pages to record essential information with space for addresses, photos, maps and a family tree.

Although designed for parents with AIDS it has already been used by people with other terminal illnesses, and in other circumstances. We have heard from a grandmother who completed a Memory Store for her grandchild who was placed for adoption outside the family; a children's worker is completing a Memory Store retrospectively for a young child whose mother died before the work could be done. We have also heard of adults adapting the Memory Store so that they can leave a record of their life for a partner or relative.

The Memory Store package includes very clear guidance notes so that families can work on their own if no worker is available to help. Some parents have found it possible to involve their children and this has provided an ideal way

to broach discussion about the past, the present crisis, and the plans for the future.

Ideas for future development of the Memory Store, if funds become available, include the provision of the instruction book in different languages, a version adapted for use in different family separation circumstances, and a photocopy free version so that agencies could make very cheap copies for their service users.

Any comments or suggestions for changes or additions would be very welcome. Please write to Carol Lindsay Smith, c/o Barnardo's, Tanners Lane, Barkingside, Ilford, Essex IG6 1QG.

The Memory Store is now available at the reduced price of £27.00, plus £2.95 Postage and packing, from Barnardo's Publications Ltd. (address as above).

NEW MILDMAI UNIT

The Mildmay Mission Hospital in East London have opened a new Family Care Centre. The aim of the new combined care facility is to enable families to remain together at the hospital.

Facilities at the new unit include 12 large family rooms for mother/father and child, each with balcony and en suite bathroom, interlinking rooms to accommodate families in which more than one member is ill, and separate suites to allow other loved ones not requiring care to stay close by.

Mildmay provides palliative care, with its emphasis on symptom control, relief of pain and quality of life enhancement, whether the person has been admitted for respite, rehabilitative, convalescent or terminal care. An interdisciplinary team provides a range of services, including 24 hour nursing and medical cover, nursery nursing, physiotherapy, occupational therapy, and a range of complementary therapies.

Referral enquiries should be made to the Community Liaison Team, Mildmay Mission Hospital, Hackney Road, London E2 7NA (tel. 071 739 2331).

SEX EDUCATION CHANGES

HIV is to be dropped from the National Curriculum following the passing of an amendment to the Education Bill in the House of Commons in July. This does not however signal the end of HIV education in schools, nor do the changes come into immediate effect. The amendment (which now forms section 241 of the Education Act 1993):

- Requires governors of maintained secondary schools to provide sex education (including education about HIV/AIDS and other sexually transmitted diseases) to all registered pupils.
- Removes reference to HIV/AIDS, STDs, and aspects of human sexual behaviour other than biological aspects from the National Curriculum Science.
- Grants parents the right to withdraw pupils from all or part of sex education outside the National Curriculum in both primary and secondary schools. Since HIV will no longer be in the National Curriculum, parents will be able to withdraw pupils from HIV education. During the debate in the House of Lords, Baroness Blatch (Secretary of State for education) confirmed that the parental right of withdrawal would apply even if the pupil was over the age of sexual consent.

The Department for Education has written to all schools informing them that the changes will come into effect from August 1994. The Department draft circular on Sex Education in Schools (see ChildAIDS no.2) has been withdrawn, and new draft guidance taking into account the changes will be produced for consultation in the Autumn term 1993. A new circular, including models of good practice in sex education, will be issued to schools in the Spring term 1994.

The Sex Education Forum has produced a briefing on the changes to sex education provision and their implications. To obtain a copy, please send a stamped addressed envelope to the Sex Education Forum, National Children's Bureau, 8 Wakley Street, London EC1V 7QE (tel. 071 278 9441).

The 2nd International Conference on HIV in Children in Mothers took place in Edinburgh from 7th to 10th of September 1993, bringing together some 400 delegates from 40 countries. The conference was organised by the Paediatric AIDS Resource Centre in Edinburgh because of a recognition that at the larger international AIDS conferences the specific issues impacting on mothers and children are not always given sufficient emphasis.

In an intensive four day programme, professionals from a wide range of backgrounds were able to share the latest information on both the clinical and the social aspects of HIV in mothers and children. In addition to the plenary sessions and workshops, there were

2nd INTERNATIONAL CONFERENCE ON HIV IN CHILDREN AND MOTHERS

7th-10th September 1993
EDINBURGH U.K.

*A report by Neil Orr
(National Forum on AIDS and Children)*

nearly 100 poster presentations.

This does not aim to be a comprehensive report of the conference proceedings. Rather it is a summary of some of the main points that emerged in relation to children.

□ *The Paediatric AIDS Resource Centre are considering producing a more detailed proceedings (details from PARC, 25 Hatton Place, Edinburgh EH9 1UB, tel. 031 668 4497).*

*Conference abstracts have been published in the journal **Pediatric AIDS: fetus to adolescent**, vol.4, no.4, August 1993. Bold numbers in brackets (e.g. P7.2) refer to these abstracts, some of which are more detailed than others.*

The global impact of HIV on children

In his introductory speech, Dr Michael Merson (Director of the World Health Organization Global Programme on AIDS) noted that "the epidemic wave has affected millions of women and children, and millions more are threatened". WHO estimates that globally about one million children have been infected through being born to mothers with HIV. WHO also "estimates that about half of all infections to date have been in 15 to 24 year olds: infections in young people are driving this epidemic".

Merson pointed out that "in the developing world, the peak age of infection tends to be lower in girls than boys". As the receptive partners in heterosexual intercourse, women are more at risk than men, and "The risk of infection may be greater still in adolescent girls, as their more immature genital tract may be a less efficient barrier to HIV".

Janet Mortimer (43) reported that

in Europe there have been over 4,000 cases of AIDS in children under 15, with over half of these (2,209) in Romania. Here in an attempt to compensate for poor nutrition, children were infused with unscreened blood using unsterile equipment. An emergency plan put into action in 1990 has reduced the number of new cases. Elsewhere in Europe, the highest rates of HIV infection in children are to be found in Spain, France and Italy.

In the UK, the Edinburgh region (7) has been particularly affected by HIV/AIDS. However the prevalence of HIV in pregnant women has declined from 1 in 200 in 1986 to 1 in 1000 in 1992. This may be because amongst women the epidemic in the city has largely involved those exposed to a drug-related risk factor in 1983-5, and this cohort may have increasingly finished childbearing.

In New York (48), children were born with HIV as early as 1977,

and by the end of 1992 there had been 1071 cases of AIDS in children under 12. About 1500 babies a year are now being born to mothers with HIV in the city. 62% of mothers of children with AIDS have been injecting drug users. In the USA as whole 77% of children with AIDS are of black or hispanic origin.

Angus Nicoll (47) emphasised the need for more precise estimates of the extent of HIV in Africa given that "Direct epidemiological data on child mortality and morbidity attributable to HIV-1 in Africa are sparse". He outlined a model for estimating the impact of HIV on child health.

Estimates of the extent of the epidemic can help us to plan our responses to it. Whatever the exact figures though, the impact of HIV is undeniable, prompting Dr Mhloyi from Zimbabwe (herself a demographer) to remark: "I don't need a number, I don't need a statistic - I live with it".

Mother-to-child (vertical) transmission is the main cause of HIV infection in children, with infection taking place during pregnancy, during childbirth, or during breastfeeding. Rates of vertical transmission vary in different parts of the world, as was illustrated in data presented in Edinburgh. In a study from Ireland (P3.2) 11.6% of children born to mothers with HIV were infected, compared to 56% of a small group (18 children) in Angola (P3.4).

The mother's state of health seems to be one factor affecting the likelihood of transmission. F. Meier (P4.1) compared 14 mothers of infected children with 43 mothers of non-infected children, and found that the former group had significantly lower CD4 cell counts (associated with more advanced disease progression). Similarly a study from Brazzaville, Congo, found that women who had symptoms during pregnancy were more likely to pass on the virus to their child (24).

A study from Yale (23) found that the first-born child of an HIV positive mother was more likely to be infected than children born subsequently (25% compared with 18%). Furthermore if the first-born child was HIV+, there was a 37% risk of a subsequent sibling being HIV+, compared to only 6% if the first-born was negative. In relation to birth, V. Lefevre in Paris (22) found that the duration of labour made no difference to the likelihood of transmission, but prolonged membranes' rupture increased the risk.

Attention is now being focused on strategies for interrupting vertical transmission. In the USA, approval has been given to the ACTG076 trial which is testing AZT as a means of preventing mother-to-child transmission. First results are expected in Spring 1994. An earlier study by Dr Sperling and colleagues with 43 women found no serious toxicity in infants. Another question requiring investigation is whether the use of AZT in pregnancy could lead to children being born with AZT resistant strains of HIV.



The standard HIV antibody test widely used with adults cannot give an accurate diagnosis for up to the first 18 months of life, as children may be born with their mothers' antibodies to HIV. Other tests have been developed, and further future methods were suggested in Edinburgh. For instance, a Milan study (P2.2) suggested that T-cell changes could be used in early diagnosis, since these appear to differ in HIV-infected children.

Many methods of HIV testing can only be carried out in specialised laboratories, although this is likely to change as more testing kits come on to the market. The pharmaceutical company Roche organised a pre-conference symposium to publicise its new Amplicor HIV-1 kit, based on the Polymerase Chain Reaction (PCR) method. PCR has been used for the early diagnosis of HIV in children, and Dr Spadaro of Roche (P2.9) claimed that the Amplicor kit is "a rapid and reliable test". Dr Mortimer (PHLS) welcomed this, although he stressed that it "can't be seen as the total panacea" as false results are still possible in some cases.

Another suggestion was that the presence of IgA antibodies could be used in the early diagnosis of HIV. A study carried out in Zaire found that the "the presence of IgA anti-HIV at or after 3 months... was a strong indicator of infection" (P2.11), and this could be detected using "a simple modification of a widely-used method" that "could be transferred to services in developing countries".

There was also discussion of the ethics of testing. In France, proposals for mandatory HIV testing of pregnant women were narrowly defeated recently, but had the support of two major doctors' organisations. Dr Chevallier (Paris) commented that HIV testing may be followed by women being pressured to have an abortion, and that there have been cases of such women "going underground" and giving birth completely outside of health services.

HIV in Children

In the main presentation on the natural history of HIV in children, Dr. S. Blanche stated that there are "more similarities than differences from the disease in adults". One difference is that there is a bimodal evolution of the disease in children, with children either becoming seriously ill in the first year of life or else having a good chance of living for some time without illness.

In a major French study (to be published shortly), 12% of children developed opportunistic infections - the main cause of death - in the first year. After this, the risk of developing these rises very slowly. One third had no symptoms at all at the age of five years, and Dr Blanche predicted that "a large number of children will reach adolescence". The situation may vary around the world however: in a study in Zaire (P4.1), 87% of infected children display-

ed some symptoms within twelve months.

The child's prognosis is strongly related to the stage of the mother's disease. In the French cohort study, children were more likely to develop AIDS quickly if their mother had AIDS at the time of delivery. It has also been hypothesised that children infected in utero, rather than at birth, may be more likely to develop AIDS at an early stage. Small studies have reached different conclusions on this, and in any event there have also been cases of early progression to AIDS in children who were known to have been infected around the time of birth (e.g. through a blood transfusion).

In adults CD4 cell counts are widely used as an indicator of disease progression, and in the USA guidelines have now been issued for when to start drug therapy in children based on these (see *Pediatric Infectious Disease Journal*, Ju-

ne 1993, p.513-22). However Dr Giacquinto (Padova) emphasised that the usefulness of CD4 counts in children has not been conclusively demonstrated. A small Spanish study (P2.10) found "a slow and progressive decrease in CD4 levels" in infected children, but that there was no "relationship between CD4 counts and clinical evolution".

Early US studies suggested that almost 90% of infected children had neuro-developmental problems. However a New York study (38) found much lower levels, with 6% of children having definite learning disabilities (36% had a significant language problem).

HIV may not be sole cause of such problems in affected children. A Kampala study (P5.4) found that psychomotor development was delayed in both infected and uninfected children born to HIV positive mothers, with psychological, social, and other factors playing a possible role.

Older Children

Dr Jim Oleske (I25) gave an interesting presentation on HIV in older children. At this early stage in the pandemic, we still do not know what the long term effects of HIV will be on those children born with the virus as they grow up.

Dr Oleske and his colleagues in Newark are following a cohort of 42 children over the age of nine. Children who survive longer may develop long term problems with various organs. For instance they may develop chronic respiratory problems similar to cystic fibrosis. There will be a need to develop rehabilitative programmes for such children.

In terms of child development, the effects of HIV do not seem to have been as drastic as some earlier pessimistic predictions. 83% of the children are attending regular schools, where most are performing as well as other children. Long term follow up of a French cohort of children has also found that most have fallen in the normal range for psychometric tests.

Oleske emphasised the need for general supportive care for children, which does not only treat the disease but also seeks to minimise the effect of the disease on development, and to minimise the disruption of family life.

There is a need for good communication with children, and Oleske expressed concern that 43% of children in the Newark cohort are unaware of their infection. With 76% of the children having experienced the death of their mother, there is clearly a need for "age appropriate discussion of death with children".

Although the onset of puberty may be delayed in some children (due to "failure to thrive"), some children born with HIV are now reaching the age where they will be able to have children of their own. We may soon see cases of second generation mother-to-child transmission of HIV.

Treatment

Debate continues about when to start treatment with AZT in children. In some centres in Italy for instance it is provided to asymptomatic children, while in Switzerland only children who have developed AIDS are treated with AZT. The Concorde trial has called into question the value of early intervention in adults, though Dr Giaquinto (Padova) felt that it might be more useful in children, who have a developing immune system. He stressed that doctors should explain to parents and children what is known, and what is unknown, about particular treatments.

There was caution about what progress has been achieved so far. A US study of 96 infected children (30) found that "the survival of children born between 1989-91 (after routine use of AZT) is no better than for those born between 1986-1988" and that "Early mortality has not

decreased with advances in medical care".

Dr Ed Connor reported that hopes that combination therapy with different antiretroviral drugs (e.g. AZT and ddC) might make a significant difference to survival have not so far been supported by the results of adult trials. No data is available on children.

The ways in which drugs are administered affect their suitability for children. Aerosolized pentamidine is used to prevent *P. Carinii* Pneumonia in adults. It has not been recommended for use with young children, even though PCP is a major cause of infant mortality, because of the need for patient co-operation (the drug is delivered via a face mask). However, on the basis of an Italian study (P6.5), P. Marchisio and colleagues now suggest that it "can be effectively, safely and easily administered to children of all ages to prevent PCP".

Social Aspects

As Dr Jonathan Mann emphasised, there are distinct "societal risk factors" for HIV, with groups that are discriminated against or otherwise socially deprived being particularly vulnerable. For instance, in Latin America homeless street children are at risk, with sexual transmission of HIV being found in children as young as 6 years old (44). Social factors also influence a child with

HIV's life expectancy: again from Latin America it was reported that "Survival periods were greater in children of higher social and economical status".

Families affected by HIV may also suffer from a range of social problems such as poor housing and poverty, as was highlighted in a study of 304 affected children in Paris (P8.1). 53.4% of mothers had no individual housing (with 29.9% homeless, squatting or living in lodgings) and 62% were dependent on state benefits as the main source of income.

Living with HIV can create additional problems. A study from Sweden (35) of 144 affected children concluded that many were in "a vulnerable social situation". Families were often isolated, with only 24% having "support from relatives or friends who were aware of the family being HIV affected". Children may often experience discontinuity of care: in the Paris study 45% had lived through environmental changes (parental separation or death, placement in foster care or in extended family, adoption).

This does not mean however that most children are neglected by their parents. A French study (P7.4) of mother-child relationships concluded: "Despite their dramatic situation, many mothers [with HIV] have established a rich and protective relationship with their child. Some were able to... discover a 'resource' potential unknown until now, from which the child can benefit". It is important to give "mothers confidence in their capacity to be good enough mothers and to help them rely on their family circle and social support".

Whatever the benefits of AZT and similar drugs, they are unavailable to people in many parts of the world. However many of the health problems associated with HIV (persistent diarrhoea, oral thrush, etc.) can be treated with existing and widely available drugs and other therapies. The World Health Organisation Global Programme on AIDS has produced draft Guidelines for the Clinical Management of HIV infection in Children suitable for the developing world.

Treatment is not only a question of which drugs to use however. Dr Oleske, noting that HIV can often be "a very painful disease", stressed the usefulness of relaxation exercises in pain management. There was also a recognition of the importance of good nutritional support. Dr Mhloyi from Zimbabwe drew attention to the need to develop and utilise traditional medicine, which is often all that people have access to.

A personal view

In his closing remarks, Dr William Cutting emphasised that the conference could not be judged a success unless those present put what they had learned into practice. Nevertheless, Dr Cutting, Dr Mok, and their colleagues should be congratulated on enabling people to learn about so much in such a short time.

In such a large and diverse gathering of course not everybody will be completely satisfied. Some felt for instance that there was too much emphasis on a US/West European perspective, others that not enough provision had been made for people with HIV to attend. There were suggestions that future conferences should focus on families rather than just mothers and children, and on youth as well as children.

None of these issues can be easily resolved. The underrepresentation of the developing world is a function of global economic inequalities, rather than just a matter of conference planning. Participation by people with HIV can be beneficial for all, but it sometimes seems to be just a tokenistic exercise rather than a real attempt to meet the needs of such people. And in broadening the scope of the conference, the focus on mothers and children may be diluted.

These are issues of substance which will need to be addressed by whoever takes on the responsibility of organising the 3rd International Conference.

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Services for children and families

Dr Chevallier (Paris) observed that "the child often disappears behind the diagnosis of HIV/AIDS" (15), and that we need to see the child in the family context. We must also be careful not to present the child as the "innocent victim" of "guilty parents". Services should be adapted to the needs of families, and to the fact that many come from minority communities. Specific HIV services however may further marginalise children and stop us using existing structures with their experience of caring for children with serious illnesses.

Joy Barlow of the Aberlour Child Care Trust (17) works with women drug users in Scotland, and said that "such women don't expect a good deal" from services "and they don't always get it". She stressed that "we have to work at a woman's pace, to enable her to make decisions... we cannot intervene arbitrarily and remove her control". Children affected by HIV need to be given the chance to talk, to look at their future, and "to have as normal a life as possible".

Substitute care:

Gerry O'Hara (131) reported that Lothian Regional Council has provided foster care services to more than 80 affected children since 1986. In keeping with the principle that "normal services available to other families should be used" wherever possible, Lothian have developed the skills of existing foster carers rather than set up specialist services. Since in most cases social services do not know if children are HIV+, they are unable to guarantee to foster carers that any child is uninfected. Lothian's policy therefore is that all carers have to be prepared to work with children with HIV.

In Paris though, where 1/4 of children born to mothers with HIV have been in care, there have been difficulties finding foster carers for infected children (45). A network of families has been established especially to care for such children. These families have to be willing to maintain contact with the natural parents, and to work closely with the foster care team. Children with HIV cannot be placed with families where there are other children under 12, because of concern about possible adv-

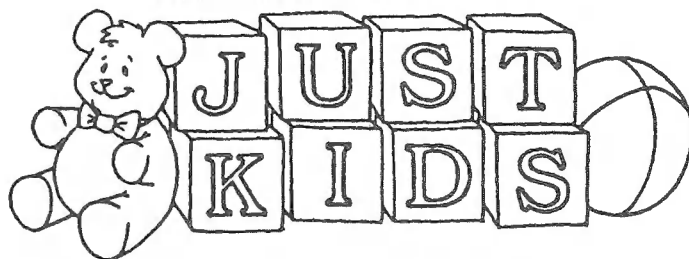
erse effects on younger children.

In Romania (46, P8.15) children up to the age of three can be placed by their parents (for medical, social, or family reasons) in institutions called leagans. Around 30,000 children live in such institutions, 2330 of them infected with HIV. In the past conditions in leagans were very poor, with inadequate nutrition and little play or stimulation (children were often kept in cribs all day as a means of control). There has been some improvement recently however.

Voluntary organisations:

Around the world there are many groups of volunteers providing practical assistance to families affected by HIV. Organizations like the Teresa Group in Toronto (19), Arche in Milan, Solidarite Enfants Sida in Paris (P7.2), Grandma's (P8.3) and ACET (20) in Britain, provide a range of services such as trans-

HIV Positive Children Are



Just Kids is a newsletter produced by ACT UP Pediatric Committee, 135 West 29th, 10th floor, NYC 10001, USA.

port and childcare. There are also activist groups like the ACT UP Pediatric Committee in New York (P8.9), which successfully campaigned for foster care children to be allowed to take part in clinical trials.

Health services:

A study from Atlanta, USA (P8.5) confirmed the usefulness of a family-centred model of health care delivery. An assessment found that 70% of parents were not receiving health care for their own HIV disease, and that families were experiencing problems with multiple clinic visits on different days. A Family Clinic was set up to provide health care and social services to children and parents in a single setting. The number of clinic visits per family has now been reduced by 40%.

A New York study (P8.6) found that "children with AIDS specialist care had a 37% lower risk of death than those without specialist care".

SCOTLAND'S CHILDREN

Sarah Morton of Children in Scotland reviews the new White Paper on child care law, and asks whether it provides adequately for children and families affected by HIV.

In August the Scottish Office published **Scotland's Children: proposals for child care policy and law**, the long awaited White Paper reviewing child care law in Scotland. The Scottish Child Care Law Review Group was established in 1988 with the remit to identify options for change and improvement in child care law, which would simplify and improve arrangements for protecting children at risk and caring for children and families in need. The Review Group's report was published in October 1990, since when major inquiries and reports have made recommendations incorporated into the White Paper, including Lord Clyde's report on Removal of Children from Orkney (1992) and the Scottish Law Commission's Report on Family Law (1992).

The paper contains various recommendations in the form of legislation, regulations and guidance - a programme that will take several years to complete. The general reaction of those working with children is that the paper falls short of an equivalent of the Children Act now in force in England and Wales. Margaret MacKay, Director of ChildLine Scotland said *"The paper represents a missed opportunity to integrate public and private law for the benefit of Scotland's Children"*. Concern has also been expressed that the White Paper

er suggests far more guidance and regulations than legislation, which means that much will not be open for public debate.

However the White Paper has been welcomed for its positive aspects, and some of these are of particular significance for those working with HIV affected families. There is an emphasis on children's rights and listening to children, although these principles are often unmatched by proposals for policy or services. Included in this is that children have the right to express their opinion on matters affecting their future and that their opinions are to be given "due weight". They also have the right to expect that personal information about them will be handled sensitively.

There is a section on children with disabilities - the first time that children with disabilities have been profiled in a more general document on children. Significantly for families with HIV, there is a recognition of children who are affected by serious illness or disability in the family, and their entitlement to special needs assessment. Also contained in this section is promotion of *"rapid and flexible responses to the needs of families"* and a recognition of the needs of children whose parents have *"a deteriorating condition such as AIDS"*. However references to res-

pite care for children with disabilities do not make it clear whether children affected by illness or disability will also be entitled to respite care. This section also recognises the importance of multi-disciplinary co-operation in relation to children and families with illnesses or disabilities.

Section 3.3 of the White Paper suggests a *"general welfare duty"* for local authorities. However this is seen as a watering down of both Section 12 of the Social Work (Scotland) Act 1968 and of the suggestion in the Scottish Child Care Law Review. This clause enables rather than obliges local authorities to provide services, and there is not a category of "children in need" which raises concern about the ability of families affected by HIV to access services. At present the exact remit of the general welfare duty needs clarification.

At present then, the White Paper seems to fall short of a Children's Act for Scotland, although the exact form of legislation is still unclear. The process of consultation and further development will make this apparent, during which the needs of children and families affected will be represented to the policy makers through a variety of channels.

Scotland's Children: Proposals for child care policy and law (CM 2286) available from HMSO, priced £7.85.

SCOTTISH GUIDANCE PUBLISHED

Children and HIV: Guidance for Local Authorities and Voluntary Organisations was issued by the Scottish Office in September, after a consultation process which started in August 1992. The resulting document is essentially a Scottish version of the guidance relating to England and Wales, published by the Department of Health in December 1992. Surprise has been expressed at this, especially as the draft used for consultation purposes did not bear such a close resemblance to its English/Welsh counterpart. There will be a fuller report on the Guidance in the next issue of **ChildAIDS**, following a Children in Scotland seminar on the Guidance at the end of October.

Copies available from: Social Work Services Group, Room 420, 43 Jeffrey Street, Edinburgh EH1 1DN.

CHILDREN AND HIV RESOURCES LIST

This new publication from Children in Scotland draws together a wide range of leaflets, books, and videos for working with children and families. There are sections on material for younger children, and on bereavement, as well as a comprehensive list of materials for parents, carers and professionals. The lists will be updated on a regular basis, and provide a single reference point for the diverse range of material on HIV and AIDS in children and families.

Children and HIV resources list: material on HIV and AIDS for children, their parents, and those who work with them, available for £1.00 a copy from Children in Scotland, Princes House, 5 Sandwick Place, Edinburgh EH2 4RG (Cheques should be made payable to "Children in Scotland")

CHILD PROTECTION

The July meeting of the National Forum on AIDS and Children focused on child protection issues for those working with families affected by HIV. The discussion was introduced by Simmy Viinikka (Terrence Higgins Trust), Heather Andrews (Hammersmith and Fulham Social Services), and Sarah Borthwick (British Agencies for Adoption and Fostering), and was followed by contributions from both child protection and HIV workers. The following summarises some of the main points that emerged.

□ Children have a right to be protected from emotional and physical abuse, and from neglect. Evidence suggests that there is a significant amount of abuse across society, with abuse being perpetrated by a wide range of people - parents, carers, professionals, etc.

HIV is not in itself an issue for child protection, and there is no evidence that abuse is more likely in families affected by HIV. Equally there is no evidence that it is less likely in such families. Agencies working with any families need to be aware of the possibility of child abuse.

□ Under Section 47 (1) of the Children Act, local authorities have "a duty to investigate" where "they have reasonable cause to suspect that a child... is suffering, or is likely to suffer, significant harm". Other statutory agencies such as health authorities and education authorities have a duty to assist such investigations by providing relevant information etc.

Apart from the NSPCC, voluntary organisations are not legally obliged to report cases of suspected child abuse, but it is certainly good practice to do so, and most voluntary childcare agencies do have policies to this effect.

□ Staff in traditionally adult-focused HIV agencies may be unaware of what the indicators are for child abuse, and what to do if child abuse is suspected. HIV agencies and local child protection teams should establish links in order to gain a clearer picture of each other's roles. HIV workers could attend local authority multidisciplinary child protection training courses (e.g. London Lighthouse workers have attended the Kensington and Chelsea course).

Hammersmith and Fulham social services are developing an agreed strategy between childcare and HIV teams, setting out how to deal with abuse issues, and who should be involved at what stage. For instance it has been agreed that in cases of child abuse within families affected by HIV, the HIV status of the child or the parent is not relevant in case conferences.

□ Where child abuse is suspected, HIV agencies should contact the local child protection teams, rather than attempting to deal with it themselves. However, adult-focused HIV agencies may fear that they will lose credibility with their clients if they involve social

services. In such cases, workers should focus on the child's needs and rights, not solely on the adult's concerns, and not on the worker's need to maintain a relationship with the adult client. The first step should be to discuss concerns with the parent(s) - there is something wrong with the worker/client relationship if this is not possible.

There may also be concerns about breaching confidentiality; indeed there may be a conflict of cultures between child protection teams with an emphasis on sharing information and HIV teams whose primary concern is confidentiality.

"HIV in itself is not a reason for considering child protection procedures... What is at issue is whether there are sufficient grounds for considering that children are at risk of significant harm"

Department of Health
Children and HIV
Guidance

Confidentiality policies need to be developed which allow for disclosure in cases of suspected child abuse. For instance, all parents using the services of Barnardo's Positive Options are informed that confidentiality will be maintained, but that "in exceptional circumstances if we were concerned about the health or safety of a child or young person we would be obliged to pass on information. If at all possible we would discuss this with you before taking any such action." They have had no objections to this from parents.

□ It is not just parents who abuse children. Home Office guidelines recommend that all staff or volunteers with regular substantial unsupervised access to children should be police checked for previous convictions. Some HIV agencies have already started doing this. Others may be concerned that this may lead to discrimination (e.g. against gay men convicted of sexual offences not involving children); however it is at the discretion of the agency whether they regard an offence as significant.

With or without police checking, care must be taken with the recruitment, support, and supervision of all those working directly with children.

Further reading:

The key documents for those working in this area are:

Working Together under the Children Act 1989: a guide to arrangements for inter-agency co-operation for the protection of children from abuse (HMSO, 1991).

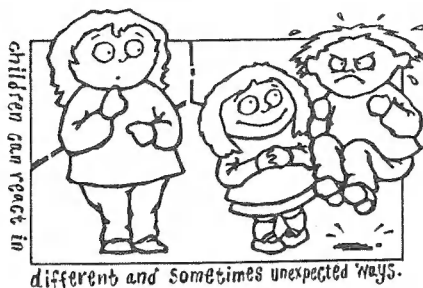
Children Act 1989 Guidance and Regulations Volume 1: Court Orders (HMSO, 1991).

Children and HIV: guidance for local authorities (Department of Health 1992), especially Chapter 12 on child protection.

PUBLICATIONS

□ Barnardo's / Terrence Higgins Trust booklets.

Barnardo's and the THT have published new, updated editions of two jointly produced booklets (originally published in 1991). **What can I do about AIDS?** is aimed at secondary school children, and includes a colour photo story focusing on young people's attitudes to HIV.



from: *AIDS in the family*

AIDS in the family: information for parents and carers is aimed mainly at families directly affected by HIV or AIDS. It covers such issues as confidentiality, testing, and emotional support.

Free sample copies are available from Barnardo's, Tanners Lane, Barkingside, Ilford, Essex IG6 1QG (tel. 081 550 8822). Further copies cost £1.00 a set.

□ Research into the needs of children and young people infected or affected by HIV/AIDS in the Bradford Metropolitan district - Tracy Race (Barnardo's Yorkshire / Bradford Metropolitan Council Social Services, 1993).

A review of the current position, with recommendations for future service development. Its proposals include *"The development of clear policy*

guidelines", *"a planned programme of sex and health education"* for young people looked after by social services, and defining *"children infected or directly affected by HIV to be priorities as being children in need"*.

Details from: Barnardo's Yorkshire, Four Gables, Clarence Road, Horsforth, Leeds LS18 4LB.

□ It's clinic day - Ruth Stevens (2nd printing, Lothian Health Education Department, 1993).

A colourfully illustrated book telling the story of a child visiting the clinic for check ups because her mother has HIV. Suitable for children aged 3 to 8 years old, it was written by a HIV positive mother to help parents and others introduce the subject of HIV in a sensitive way to children.

Available free to individuals or agencies in the Lothian area, £1.15 per copy (plus post and packing) to others, from: Carol Milligan, Lothian Health Education Dept., 61 Grange Loan, Edinburgh EH9 2ER (tel. 031 447 6271).

□ HIV, the church, and African communities in London (London Ecumenical AIDS Forum, 1993).

This report of an awareness day includes an interesting contribution on the needs of African families living in Britain by Dorothy Muk-

asa. Mukasa notes that *"There is a desperate shortage of registered African carers across the whole of London"*, and argues that with *"the rising number of African children orphaned by HIV and AIDS"* there is a need for a London-wide drive to recruit African child carers.

Available for £2.50 from the London Churches HIV/AIDS Unit, St Paul's Church, London SE17 3QU (tel. 071 793 0338).

□ Measures to decrease the risk of mother-to-child-transmission of HIV infection - ed. C. Peckham and M-L. Newell (Colwood House / Wellcome, 1993).

Proceedings of an international meeting held in London in January 1993, with contributions on risk factors for vertical transmission, mode of delivery, role of antiretroviral agents, etc.

Published by Colwood House Medical Publications, Kirtons Farm, Pingewood, Reading, Berks. RG3 3UN.

ALSO OF INTEREST...

My mum needs me: helping children with ill or disabled parents - Julia Segal and John Simkins (Penguin, 1993, £6.99).

Includes material on how children view parents' illness, the effect of such illness on a child's development, ways of communicating with children about parents' illness, and helping children to cope with the death of a parent.

Talking to children when an adult has cancer (Cancerlink, 1993).

Thirty-four page booklet giving practical advice on how, what, and when to tell a child that somebody close to them has cancer. It explains how children might react, what questions they are likely to ask, and what to do when a child is upset.

The booklet takes the view *"that it is helpful for everyone if children are involved in the events that are affecting the family. Children who are informed openly are likely to be more resilient, independent and secure"*.

Cancerlink have also produced a useful reading list on children and bereavement, including books for children.

Details from: Cancerlink, 17 Britannia Street, London WC1X 9JN (tel. 071 833 4963).

Teenagers in hospital (Action for Sick Children, 1993).

This pamphlet is for young people in hospital (though it would also be helpful to staff working with this group). It aims to help them think about consent to treatment, and gives ideas on how to ask nurses and doctors questions that might be worrying them. A questionnaire is also included to enable young people to express their views about their stay in hospital to staff.

Details from: Action for Sick Children, Argyle House, 29 - 31 Euston Road, London NW1 2SD (tel. 071 833 2041).

COURSES AND CONFERENCES

17 November 1993: **Children and families affected by HIV/AIDS - who cares for the child?**, Manchester. A North West Medical Group seminar organised by British Agencies for Adoption and Fostering. Details from Rose Lang, BAAF, 11 Southwark Street, London SE1 1RQ (tel. 071 407 8800).

25 November 1993: **Religion, ethnicity, and sex education: exploring the issues**, London. Organised by the Sex Education Forum. Details from Conference Office, National Children's Bureau, 8 Wakley Street, London EC1V 7QE (tel. 071 278 9441).

7 - 8 December 1993: **Supporting children and families affected by HIV and AIDS**, London. Two day course at the London Lighthouse, 111-117 Lancaster Road, London W11 1QT (tel. 071 792 1200).

10 December 1993: **Choosing the future: running a young people's HIV prevention needs assessment**, Sheffield. Details from: Sheffield Centre for HIV and Sexual Health, 22 Collegiate Crescent, Sheffield S10 2BA (tel. 0742 678806).

10 February 1994: **National Forum on AIDS and Children** meeting, London. The rights of children and young people affected by HIV/AIDS (venue to be arranged).

14 -15 April 1994: **Child care workers and HIV**, Edinburgh. Residential course organised by the Paediatric AIDS Resource Centre. Details from PARC, 25 Hatton Place, Edinburgh EH9 1UB (tel. 031 668 4497).

10 June 1994 (provisional date): **Scientific update on HIV in women and children**, Edinburgh. Meeting aimed at clinicians and practitioners interested or involved with children and HIV, organised by PARC (details above).

7 - 10 July 1994: **AIDS Impact- 2nd international conference on biopsychosocial aspects of AIDS and HIV infection**, Brighton. Conference topics include children, and the family. Details from: AIDS Impact Conference Organisers, c/o Dept. of Psychology, St Mary's Hospital, Praed Street, London W2 1NY.

If you would like to publicise a course or conference in ChildAIDS, please send the details to the editor (address on page two).

SUNDAY TIMES (continued from page one)

18 months of life, because of the presence of maternal antibodies. Estimates of the proportion of infected children born to mothers with HIV vary from 14% to 40%, with studies in Africa tending towards the higher figure. Thus, we would expect at least 60% of babies who test HIV antibody positive in the first months of life to be in fact HIV negative.

Babies give lie to African Aids

by Neville Hodgkinson
Nairobi

FATHER Angelo d'Agostino is puzzled. He sits at the heart of Africa's alleged Aids crisis.

home opened and only one of his first 45 children has been lost — an ailing six-week-old infant who had to return to hospital almost immediately and died two weeks later. The rest, who are aged up to six years, are thriving and...

Headline in the Sunday Times, 29 August 1993

What of the children in Nairobi who are infected with the virus? In a major European study, less than one in ten children with HIV died in the first year of life, while almost half were still alive at the age of nine. In Africa, children might be thought to have a generally poorer prognosis, given poor levels of health care, nutrition, etc. in many areas. But for those being properly fed and cared for in places like the Nyumbani hospital, there is no reason to believe that most would die in "two or three months".

Despite the small numbers of children involved, and the fact that they may well not have been a representative sample (for instance, are healthy children, rather than those already seriously ill more likely to be referred to Nyumbani?), the Sunday Times has no qualms about extrapolating from anecdotes to the African continent as a whole. This has to be seen in the context of an ongoing campaign by the paper to downplay the significance of AIDS, chiefly by denying a link between HIV and AIDS. It is a campaign that would seem to be driven more by political considerations than by any concern with facts.

CHILDAIDS RESEARCH SUPPLEMENT:

It is planned to produce a supplement in a future issue of **ChildAIDS** on research in progress on children and HIV in the UK. If you are involved in a research project in this area (whether related to prevention, health care, psychosocial aspects, etc.), it would be helpful if you could supply a short report.

The report should include a description of the project and its current stage (100 - 200 words), the names of individuals and institutions involved (with a contact address), the source of funding, and details of any publications. Any supplementary documentation would also be welcome. Please send your reports, if possible by January 10th 1994, to Neil Orr (address page two).